

POLIO NETWORK NEWS

International Polio Network

4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

Polio Network News is an international newsletter for polio survivors, support groups, physicians, health professionals, and resource centers, to exchange information, encourage research, and promote networking among the post-polio community.

Annual Membership:

\$8.00 (USD* only) for polio survivors.

\$15.00 (USD only) for health professionals.

(Add \$3.00 for postage outside the U.S. and Canada.)

*U.S. Dollars only

Editor:

Joan Headley

Publisher:

Gazette International
Networking Institute
(G.I.N.I.)

4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

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Winter 1988 • Vol. 4, No. 1

The Politics of Disability in Relation to the Post-Polio Movement

By Phyllis Rubenfeld, Ed.D., Professor, Hunter College, New York City. (Polio survivor)

Webster's defines advocacy as "pleading the cause of another." As many of you know, nobody speaks for me, and I hope the same is true for you. We should not be in the business of delegating our authority to others. Instead of writing about advocacy per se, I would like to discuss the politics of disability in relation to the post polio movement.

Let's briefly look at the history of the organization of disability groups. Most disability groups, like the March of Dimes or United Cerebral Palsy, for example, were founded by parents of disabled children. They were organized around a single disability and their main purpose was to raise money for services, because the children's needs were not being met by government agencies. A secondary, but very important, function was to provide group support for parents. My mother recently told me about her experiences with the March of Dimes. She particularly remembered a social worker who talked to hundreds of parents at a meeting, emphasizing forcefully the importance of raising children who had polio with a sense of independence and of encouraging them to try what at first would seem impossible. The social worker repeated over and over again that parents had to be strong and not give in.

It was not until years later, when the children that these groups were founded to help were themselves adults, that disability groups became politicized. The inspiration for the disability rights movement came, naturally, from the civil rights movement of the 1950s and '60s, as did the idea that broad coalitions of individual groups could accomplish more in the political sphere than the individual groups could alone.

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Thus, it was in the early 1970's, significantly, that the American Coalition of Citizens with Disabilities was founded, based on the notion that disabled persons had more in common than not.

Of course, just as we were coming to this realization, so was the government. And just as the black civil rights movement was given its poverty programs, the disability rights movement was "rewarded" with independent living programs. There is a natural tendency to relax after a major victory, to get caught up in the day-to-day details of new programs, and to lose one's political edge. This is especially dangerous with movements like ours. And government programs are double-edged swords in any event: for administrative reasons, they encourage separate services for different disability groups, thus destroying the unity so laboriously achieved, and they co-opt the leaders of the movement with attractive executive directorships.

What does all this have to do with the post polio movement? This movement, too, arose in a pre-existing climate of segregation, and its focus has been research and fundraising, two functions that are basically unsupported by government. And the group support function has been vitally important: support groups provide us with valuable information, alleviate fear of the unknown, give us a sense of identification with others like ourselves, and provide some comfort in sharing with others. They also give us a place to talk about our problems. But therein lies the problem; we talk so much, and so forcefully, that often we come to believe that we are actually doing something, just by talking. But are we? How many of us have actually changed our ways

of life by talking? And if we have changed, how much time did we waste talking over, under, around, and through the issues before we took any real action?

So where do we go from here? I don't mean to suggest that every post polio group has to take an active political role, but I am convinced that some of them must, and I hope this will soon come about with the assistance of Gini Laurie and the International Polio Network, which has set up a network throughout the world.

We should also try to profit from the example of the black civil rights movement once again. That movement has had a hiatus during the Reagan years, but they are on the rise again -- forming new coalitions around a variety of issues, from the domestic matters emphasized by Jesse Jackson's Rainbow Coalition to human rights abroad, especially in South Africa.

Newsletters and conferences like this one* can play a role, too. There are so many of us from all parts of the country. We can cover a lot of territory.

But one way or another, we disabled people must return to the streets, engaging in civil disobedience if necessary, to regain the force behind the force that we have been for so many years.

* Third Annual Post Polio Seminar in Meriden, CT October 30, 1987, sponsored by the Post Polio Support Group of Southern Connecticut and Gaylord Hospital.

Support Group Philosophy

The goal of a support group is to empower its members with the tools necessary to make adjustments needed to continue a life of dignity and independence.

Support group(s)...

...share a common health concern.

...govern themselves and their agenda with success dependent on each member's feelings of ownership.

...may use professionals as resource persons but not as leaders.

...provide non-judgemental emotional support.

...gather and share accurate and specialized information.

...membership is fluid - newcomers are helped by veterans and become veterans who may outgrow the need for a group.

...have a cause and actively promote that cause.

...increase public awareness and knowledge by sharing their unique and relevant information.

...charge small or no fees for involvement and typically struggle to survive.

1988 Post-Polio Directory

The 1988 Post-Polio Directory is now available. Additions, deletions, and corrections are welcome. Please send to: IPN, 4502 Maryland Avenue, St. Louis, MO 63108. 314/361-0475.

Dart Resigns as RSA Commissioner

Polio survivor, Justin Dart, Jr. resigned in December upon the request of the Reagan administration, as Commissioner of Rehabilitation Services Administration, a position he held for 15 months.

Dart battled over policy and programs with his boss, Madeleine Will, Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS).

In making a "statement of conscience" before a House Education and Labor subcommittee on select education, Dart stated, "We are confronted by a vast, inflexible federal system which, like the society it represents, still contains a significant proportion of individuals who have not yet overcome obsolete, paternalistic attitudes about disability and, indeed, about government itself. There is a resistance to any sharing of their centralized authority with people with disabilities, their families, advocates and professional service providers, in and out of the federal government."

The RSA administers the Federal Rehabilitation Act and is the federal partner in all state and territorial vocational rehabilitation (VR) programs.

Polio survivor, Delbert Lewis, Planning Specialist for the Arkansas Division of Rehabilitation Services, comments, "Even though VR is the most successful federally funded program to date in the country, the Reagan Administration has consistently attempted to dismantle the agency. This action is another example."

Expressions of appreciation for his stand may be sent to: Justin Dart, Jr. 907 6th St. S.W., Apt 516C, Washington, D.C. 20024.

Dealing with the Consequences of Polio and Post-Polio Syndrome

By Paul Hasak, Ph.D.

The issues and concerns identified by individuals dealing with the consequences of polio and post-polio syndrome usually follow from the loss of physical function and the need for change that the loss might entail. The emotional consequences of the physical losses are similar to those seen in the grieving process and include sadness, anger, guilt, fear and feelings of being alone in the world. The intensity of these mixed emotions can at first be quite overwhelming and result in a state of "shock" whereby the emotional system shuts down or at least leaves one in a state of confusion or depression. If the emotions are allowed expression their intensity lessens over time. However, whereas the grieving process may be understandable and acceptable in the loss of a loved one, it is often not considered acceptable for other types of losses. Adjusting to the loss then becomes more difficult as you attempt to deny or avoid what you might consider "unacceptable emotions".

Changes that may be required as a consequence of loss of physical function can affect every aspect of your life - family, work roles, responsibilities, as well as your self-image. Guilt, shame and self-criticism often follow for not being able to "overcome" the symptoms. Overcoming rather than adjusting to realistic limitations is possibly in your history as an individual who had to deal with the consequences of polio. "No one knew I had polio" was the accomplishment. Now it may be more difficult to hide or overcome the physical deficits and you somehow interpret this to mean that all past efforts have been in vain and that you are a failure. Loss of

confidence and reduced self-esteem soon follow. Being unacceptable to yourself, you often fear and attempt to avoid rejection from others by withdrawing.

A sense of control and security usually accompanies having established an acceptable routine and style of living. This is threatened by the need for change. Fear of an uncertain future is increased by imagining the worse possibilities, for example, "I will be a vegetable, useless to myself or to anyone and totally dependent". Dependency on crutches, a wheelchair, or others is a change that conflicts directly with longstanding beliefs in self-sufficiency and independence.

Denial and avoidance may seem like the only way of coping. These in fact, might be helpful early on when you are overwhelmed by thoughts, emotions, and consequences you are facing. Adjustment begins when you are able to examine all of the emotional reactions unself-critically. It is then possible to begin looking at the meanings you are attaching to your situation and which are producing your particular emotional reactions. Given our tendency to overgeneralize in our thinking when we are feeling something very strongly, some of the meanings might be unrealistic and incorrect and can be changed.

Support groups can be an excellent way of beginning to deal with these psychological and emotional consequences. These groups can provide an opportunity for giving permission to feel the feelings you are having. They also allow the benefit of being understood and accepted at a time when you are feeling most alone and frightened. Finally,

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Dealing with the Consequences of Polio and Post-Polio Syndrome

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groups provide an opportunity to acquire information and learn how others are dealing with their situations. Individual counselling is also available to aid in identifying the unique meanings you are attaching to your situation at a time when emotions are high and interfere with the ability to maintain focus and objectivity. Even though you might be able to get through it on your own, the support and resources available could help shorten the length of time it takes and perhaps even ease some of the pain of the struggle.

Dr. Hasak, graduate of Rutgers University, with his Ph.D. from the University of Kentucky, is a clinical psychologist, who counsels polio survivors at St. John's Rehabilitation Center, 615 South New Ballas Road, St. Louis, MO 63141.

Post-Polio Research

Dr. Walter G. Bradley, Professor and Chairman of the Department of Neurology, University of Vermont, has been awarded a \$25,000 grant from Easter Seal Research Foundation (ESRF) for a study of the effects of exercise on persons with progressive post polio muscular atrophy.

The Vermont study is expected to show how measures of mechanical and electrophysiological parameters can be used to differentiate normal muscle from muscle affected by polio and help to define a muscle's vulnerability to overwork.

Dr. Theodore L. Munsat, Director of the Neuromuscular Research Unit of Tufts-New England Medical Center has been appointed a trustee of the

ESRF for a three-year term beginning January 1, 1988. With the other trustees, Dr. Munsat, a recognized authority on the late effects of polio, will honor grant requests that meet standards of scientific excellence and relate to services provided by Easter Seal.

Deadlines for the 1988 grants, with a maximum amount of \$25,000 are March 1, 1988 and August 1, 1988. For further information and application forms, contact the Research Department, National Easter Seal Society, 2023 W. Ogden, Chicago, IL 60612. 312/243-8400.

Changes have already been made for the 1989 ESRF grants. The maximum amount will be increased to \$40,000. Grants can be renewed for two years instead of three, and also starting in 1989, applications will be accepted once a year with a deadline of December 15 and a start up date of July 1.

Canadian Grant Awarded

Post Polio Awareness and Support Society of British Columbia (PPASS), 813 Darwin Avenue, Victoria, B.C. V8X 2X7, has received \$76,000 (Canadian) for a Health Promotion Directorate Grant.

The four phases of the project include duplication of library materials, publication of a brochure, distribution of a medical questionnaire, and production of a video featuring forms of treatment.

When Physical Limitations Strain Relationships

By Gerard J. Erker, Ph.D.

What can you do when you or another person you love develops physical limitations that cause role changes within your relationship?

Guard Your Precious Relationship - While physical limitations require rebuilding of individuals and their relationships, this rebuilding starts with the original foundation of core identities -- what makes people who they are. The way you feel about, behave toward, and think about one another will interact. Think in the present and flexibly to avoid limiting yourselves or your relationship to nurse/patient or care giver/dependent. See each other as the people you are -- man or woman, friends, spouses, lovers, children, parents. As soon as practical and to whatever extent possible, return to the responsibilities that characterized the previous relationship. If the relationship has been intimate, create the circumstances that will allow intimacy to be re-established.

Take Care of Yourself - How many times have you heard this admonition and felt more burdened on one hand or more guilt-ridden on the other? One of the best ways to take care of yourself is to knowingly choose what it is that you will do for each other. Also, your experiences have taught you how priceless your gifts are. Engage in work and leisure activities that allow you to continue to develop your own gifts. Finally, you need each other but try not to be the "only one" for the other. Establish or re-establish relationships with at least one other being who will, listen to you without confusing your needs with theirs, without judging or giving unwanted advice, and who will take your feelings and concerns seriously.

Consequently, you will retain your hopefulness and sense of effectiveness, while limiting resentment and ensuring that there will be more of you to truly "be with" the other.

Communicate - Share experiences and solutions with others outside your immediate relationship. Seek and use information from others who have had experiences similar to yours. Communicating through this international newsletter, for example, is far simpler than "re-inventing the wheel". Talk to each other in a way that allows you to make your own needs known, while demonstrating an awareness of the others' needs. Put your love for one another into action, tell each other what you really need and what you're willing to do to get it. This will clarify priorities and make for a mutually satisfying and reciprocal relationship.

The choices you make about how you will treat each other under such circumstances are vital. Consider them carefully.

Dr. Erker, a clinical psychologist at the SSM Rehabilitation Institute, 6420 Clayton Road, St. Louis, Missouri 63117, completed his internship at the University of Arizona Health Sciences Center and received his doctorate from St. Louis University.

IPN Membership Renewal Notices

In January, IPN mailed renewal notices to individuals whose memberships are due this quarter. Renew by returning the card with a check for \$8.00 so you will receive the Spring Polio Network News (Vol. 4, No. 2).

Survivor to Survivor

By Carol Barre (Polio survivor)

I read in the post-polio newsletters "you've got to adjust to doing less, and doing it more efficiently." My gut twists. Even coming from other polios, it brings up all my well-learned defenses. "That's giving in." "I'm different." These recommended adjustments pose as necessary evils, unavoidable compromises with current pain or future disability. They seem to come from an internal place of anger-fear-resignation.

That is not what I want. What I want is to learn from these new aspects of our dis-ease. If the first round with polio taught me persistence and courage, maybe there are equally valuable new lessons now.

Is there anybody else out there for whom "I can" got mixed up with "I have to"? These last few years I've been learning that I don't have to say yes to every opportunity.

...anybody else out there for whom "service to others" was a major prop that proved to me that I didn't need any help myself - thank you anyway? I'm learning that giving service without accepting service produces burnout.

...anybody else out there for whom "there's just not time" for being with nature, a leisurely hot bath, a self-massage, or meditation? I'm learning that I'm worth an investment of time and caring; that my body repays my TLC with contentment, ease, and new flexibility.

...anybody else out there for whom "putting the past behind you" did not work? I've discovered there are ways to go back and heal the past; to let go of some of the

emotional baggage I've been carrying all these years.

But at first, I have to be willing to open up the baggage and see what it is. Sometimes that's scary. For instance, I had conveniently suppressed, that when I was recovering I HATED my mother for some of the things she did to me "for my own good."

During the process I've discovered I'm a lot more like everybody else than I would have believed three or four years ago. I'm learning it's OK to be a little less "Special" and it's sure a lot less lonely.

So, rather than endorse the "You've got to adjust" approach, I propose using all these changes to become more YOU and less the person you thought you had to be to survive. Let's share ways we've learned to grow -- in grace, in flexibility, in love.

Carol Barre is writing a book about her experiences. Responses may be mailed to: 30 Terrace Street, Montpelier, VT 05602.

New Post-Polio Clinics

Manchester, NH: Dr. Paul Corcoran, Medical Director, Easter Seal Society, 555 Auburn Street, Manchester, NH 03103 (603/623-8863).

UCLA, Los Angeles, CA: Dr. Susan Perlman, Director, Reed Neurological Research Center, UCLA Center for the Health Sciences, Los Angeles, CA 90024 (213/825-1707).

Manuscripts Wanted

Poetry, short stories, and essays by polio survivors, who may remain anonymous in publication, are wanted for an anthology to be submitted to a prospective publisher. Focus of the work need not be polio-related, however, writings on the polio experience are encouraged. Topics could include: humor, personal growth and development, sex and sensuality, dreams, transcending tragedy, family adventures, memories, and relationships.

Please submit three copies of each manuscript to Barbara Pike VanDavis, 510 W. Main Street, Madison, IN 47520 by June 30, 1988. Include a self-addressed stamped envelope, for notification of acceptance or rejection. No manuscripts will be returned.

Charlene Bozarth and Sunny Roller of Polio Network serving Michigan, are working with Barbara Pike VanDavis on this project.

Out of Print

LATE EFFECTS OF POLIOMYELITIS (1985) edited by Dr. Lauro Halstead and Dr. David Weichers is no longer available from the Symposia Foundation in Miami, Florida.

List Available

Physiatrists are doctors who specialize in the diagnosis and treatment of physical disability. For a list of physiatrists in your state, contact: Ike Mayeda, Executive Director, American Academy of Physical Medicine and Rehabilitation, 122 South Michigan Avenue, Suite 1300, Chicago, IL 60603-6107. Telephone: 312/922-9366.

Support Group Leaders' Workshop

On June 3-5, 1988, support group leaders will meet at the Sheraton St. Louis Hotel to share ideas that will help inform and support polio survivors throughout the network.

Please direct questions or comments about the tentative schedule below to Joan Headley at International Polio Network (314/361-0475).

Tentative Schedule

Friday Evening (4:00 P.M. to 9:00 P.M.): Registration, reunion dinner, and displays.

Saturday Morning: Psychology of Group Dynamics, W. Joseph Connolly, Ph.D., Eileen Connolly, Ph.D., Morton May Jr., Ph.D., Communications Center #1, St. Louis, MO.

Saturday Afternoon: Hints on Newsletter Writing, Kathy Holman, Director of Public Relations, Clayton School District, Clayton, MO; Working with Health Professionals, Roberta Simon, RN, Polio Network of Illinois; The Pros and Cons of Being a Self-Sufficient Support Group, Panel Discussion.

Saturday Evening: Adjusting to Life Changes, Speaker followed by small group discussions.

Sunday Morning: Update on Late Effects Issues, Speakers with time for questions.

The deadline for the registration form, on the facing page, is May 1, 1988. Send the registration form to: International Polio Network (IPN), 4502 Maryland Avenue, St. Louis, MO 63108 after cutting off the hotel reservation form which is to be mailed directly to: Sheraton St. Louis Hotel, 910 North Seventh Street, St. Louis, MO 63101.

INTERNATIONAL POLIO NETWORK
Support Group Leaders' Workshop
June 3-5, 1988

REGISTRATION FORM

NAME _____ ACCOMPANIED BY _____
HOME ADDRESS _____ SUPPORT GROUP _____
HOME PHONE _____

REGISTRATION: DEADLINE MAY 1, 1988
\$20.00 before April 22. \$25 after April 22. \$ _____

MEALS:
\$68.00 (Includes Fri/Sat dinner, Sat/Sun continental breakfast
Sat/Sun lunch). \$ _____

If you have special dietary needs, contact the Sheraton.

TRANSPORTATION:
Airport to Sheraton: Airport limousine service runs about
every 15 minutes for \$6.00. Please pay the driver.

Airport to Sheraton: Van with a lift upon request for
\$8.00. Please pay IPN. \$ _____

Arrive: Date _____ Time _____ Airline _____ Flight # _____

Leave: Date _____ Time _____ Airline _____ Flight # _____

I use: ___ crutches ___ Amigo ___ manual w/c ___ motorized w/c ___ ventilator

Make checks payable to International Polio Network (U.S.funds).
RETURN THE TOP PORTION OF THIS FORM WITH YOUR CHECK.

Enclosed is a check for \$ _____

Please mail this form to:
Reservations Manager
Sheraton St. Louis Hotel
910 North Seventh Street
St. Louis, MO 63101

INTERNATIONAL POLIO NETWORK	
Name(s) _____	
Sharing with _____	
Address _____	Residential <input type="checkbox"/> Business <input type="checkbox"/>
City _____ State _____ Zip _____	Phone _____
Arrival date _____ Hour _____	No. of persons _____ Departure date _____
Circle preferred rates	No. of Rooms _____
June 3-5, 1988	
Return to: Sheraton St. Louis by May 3, 1988	
Single: \$65.00	Double: \$65.00
Triple: \$80.00	Quad: \$95.00
<small>IF RATE REQUESTED IS NOT AVAILABLE, NEXT AVAILABLE RATE WILL APPLY. RESERVATIONS RECEIVED AFTER SPECIFIED DATE WILL BE ACCOMMODATED ON A RATE AND SPACE AVAILABILITY BASIS ONLY.</small>	

Checkout time is 1:00 p.m. Normal Checkin time is after 3:00 p.m.	
Reservations are held until 4:00 p.m. unless guaranteed by a one night's deposit or guaranteed with one of the following credit cards: American Express, Diners Club, Carte Blanche, Visa, Mastercard or En Route.	
Credit Card _____	Exp. date _____ Type _____
HOTEL PHONE 314-231-5100	

MOVING??

Please send both old and new addresses to
International Polio Network when you move.
Polio Network News will NOT be forwarded
by your post office.

Conversion Assistance

The Physically-Challenged Resource Center, established this fall by Chrysler Motors, is now serving as an independent resource network for the physically challenged consumer, providing information on adaptive driving aids, such as hand controls, wheelchair lifts, and wheelchair tie downs.

A toll-free number, 1-800-255-9877, has been established for the center. In addition to providing information on types and the availability of driving aids, the center is assisting consumers in contacting conversion companies by providing a printout of companies that specialize in the distribution and installation of equipment.

A financial assistance program was also established. If you buy a 1987 or 1988 Chrysler product (after Oct 1, 1987) and have conversion work completed within six months of purchase, you may contact your dealer for the necessary forms. After processing, Chrysler will reimburse you dollar for dollar up to \$500. For more information write the Physically-Challenged Resource Center, P.O. Box 159, Detroit, MI 48288-0159 or call 1-800-255-9877.

Rehabilitation Gazette

Exciting new issue (Vol. 28, No.2), featuring a variety of experiences with aging, disability, and impairment will be ready in April. Rehabilitation Gazette, edited by Gini Laurie, is an international journal of independent living containing imaginative, practical, and down-to-earth life experiences written by its disabled readers. Send \$15 to Gazette International Networking Institute (G.I.N.I.), 502 Maryland Avenue, St. Louis, MO 63108 to subscribe.

Earning Power in the Home

Patricia Galbreath, who has been writing the nationally syndicated newspaper column, HINTS FOR THE HANDICAPPED, for nineteen years has compiled a quarterly newsletter for individuals striving to be more independent financially.

EARNING POWER IN THE HOME is full of ideas on how to start a business from the home, whom to contact, how to get organized, how to advertise, what others are doing, and how they are doing it.

For a subscription, send \$4 to cover the cost of postage and printing for one year to: EARNING POWER IN THE HOME, P.O. Box 368, Weatherford, TX 76086.

Amigo Accessories

Many Amigo dealers are not aware of the options and adaptations that are available. Contact the Amigo Service Department at 1-800-248-9131 and describe your specific needs.

Polio Handbook

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors edited by Gini Laurie, Frederick Maynard, MD, D. Armin Fischer, MD, and Judith Raymond utilizes a dictionary format to relate information on such topics as aging and weakness, diet, exercise, frog breathing, hospitalization, misdiagnosis, oxygen misuse, sleep apnea, vaccines and ventilators. Send \$6.00 to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108.

International Polio Network

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Calendar

March 2-5, 1988. The International Conference on Pulmonary Rehabilitation and Home Mechanical Ventilation. Marriott Hotel, City Center, Denver, CO. Contact: Louise Nett, R.N., R.R.T., Webb-Waring Institute, 4200 East 9th Avenue, Box 321, Denver, CO 80262. 303/394-7918.

April 7-9, 1988. Late Effects of Poliomyelitis and Chronic Underventilation. Sports Center of the Technological University in the Olympic Park, Munich. Contact: Uwe Frehse, Westendstr 93, 8000 Munich 2, West Germany.

April 30, 1988. Medical and Psychological Approach to Post-Polio Sequelae. Ramada Inn, Phoenix, AZ 85006. Contact: Ellen Pilcher, 1111 E. McDowell, Phoenix, AZ 85062. 602/239-4536.

May 13, 1988. Post-Polio Syndrome: Treatment, Management, and Community Resources. Holiday Inn, 55 Ariadne Road, Dedham, MA 02026. Contact: Gregg Garvan, March of Dimes, 65 Providence Highway, Dedham, MA 02026. 617/329-1360.

June 3-5, 1988. Support Group Leaders' Workshop. Sheraton St. Louis Hotel, St. Louis, MO 63108. Contact: Joan Headley, International Polio Network, 4502 Maryland Avenue, St. Louis, MO 63108. 314/361-0475.

November 3-5, 1988. First National Polio Conference. L'Hotel, Toronto, Ontario, Canada. Contact: Shirley Teolis, Ontario March of Dimes, 660 Overlea Blvd., Toronto, Ontario, Canada M4H 1B6. 416/425-0501.